

Vatican Conference on Neglected Tropical Diseases



Towards a Culture of Health that is Welcoming and Supportive at the Service of People with Rare and Neglected Pathologies

Vatican City, November 10-12, 2016

At the Sabin Vaccine Institute, we cultivate champions in diverse arenas who share our vision of a future free from preventable diseases. For a decade, our Global Network for Neglected Tropical Diseases built partnerships and generated resources to support the fight against NTDs.

We were honored to support the planning of the XXXI International Conference of the Pontifical Council for Health Care Workers, held in November 2016 at the Vatican to address the topic "Towards a Culture of Health That is Welcoming and Supportive at the Service of People with Rare and Neglected Pathologies."

Sabin's involvement in this historic event, attended by religious leaders, researchers and health care providers from more than 50 countries, is emblematic of Sabin's work to forge new alliances, and recruit and convene people who can be catalysts for change. We believe that in an increasingly diverse and globalized world, bridging boundaries and seeking common ground with diverse partners who share our values is essential to making progress on the most stubborn challenges to health and prosperity.

It is our pleasure to share this event summary with partners in the global health community in hopes of continuing the productive conversations begun at the conference and expanding the circle of relationships forged.

Sabin is proud to have played a significant role in the global fight against neglected tropical diseases (NTDs) over the last decade, mobilizing more than \$165 million in resources, generating political will among endemic and donor countries and engaging the public. Over its 10 years of existence, the Global Network helped build a movement that has succeeded at bringing several NTDs to the brink of elimination. Increased treatment has improved countless lives, but for some diseases, new tools and strategies are required. This work is a proud chapter in Sabin's legacy as we continue our mission with a renewed focus on vaccine-preventable diseases.

We at Sabin were heartened by the diverse gathering convened at the Vatican to address NTDs. As the Church launches its new Dicastery for Promoting Integral Human Development to carry this work forward, we hope partners in the NTD community will seek to involve faith leaders and faith-based health care providers in the effort to tackle diseases of poverty.

Sincerely,



Amy Finan
Chief Executive Officer
Sabin Vaccine Institute



The Road to Rome

We've all heard the proverb "All roads lead to Rome" – the simple truth that many approaches can lead to one outcome. On November 10, 2016, three years of partnership between Sabin and the Pontifical Council for Health Care Workers – along many different paths – culminated in Rome at this first-of-its kind conference.

The XXXI International Conference of the Pontifical Council for Health Care Workers was an inspiring gathering of Catholic officials, researchers focused on neglected tropical diseases (NTDs) and rare diseases, and leaders of global health agencies and organizations united by a shared commitment to relieving suffering and promoting health and human dignity. The reflections shared at the event, reproduced and summarized here, could inspire much-needed dialogue about how religious and secular healthcare partners can work together to achieve common goals.

The Pontifical Council for Health Care Workers (*Pontificio Consiglio per gli Operatori Sanitari*) was created by Pope John Paul II in 1985 to coordinate and promote the extensive health care work supported by the Catholic Church worldwide. As one of the largest social service providers in the world and an institution with a powerful moral voice, the Catholic Church is in a unique position to advance solutions to vaccine-preventable and neglected tropical diseases.

In 2013, Sabin established a relationship with the Pontifical Council's late President, Archbishop Zygmunt Zimowski, and Under-Secretary, Father Augusto Chendi, meeting in Rome to discuss the global NTD control and elimination effort and the critical role of the Catholic Church in providing healthcare and other social services around the world, particularly in poor communities at risk of NTDs. In 2014, after receiving an invitation to speak at the launch of the second progress report of the London Declaration on NTDs, Archbishop Zimowski shared in a letter to conference participants that the Pontifical Council, in an effort "to make strengths converge and to animate public opinion" about NTDs, would host an "international scientific congress" at the Vatican to

address the topic of "diseases of solidarity" – both rare and neglected tropical diseases.

Encouraged by the Pontifical Council's growing interest, Sabin continued outreach to the faith-based community. At the end of 2015, during Pope Francis' first visit to Africa, in a speech to U.N. officials in Kenya, Pope Francis urged, "Certain health issues, like the elimination of malaria and tuberculosis, treatment of so-called orphan diseases, and neglected sectors of tropical medicine, require urgent political attention, above and beyond all other commercial or political interests."

Sabin's dialogue with the Pontifical Council continued into 2016 as planning for the conference accelerated. After a long battle with cancer, Archbishop Zimowski, president of the Pontifical Council, passed away in July. He will be remembered as a compassionate leader in the effort to improve global health whose commitment to addressing the health needs of the poor was integral to the decision to host the International Conference.

In August of 2016, Pope Francis announced the creation of a new Dicastery for Promoting Integral Human Development to combine and expand the work of the Pontifical Councils of Justice and Peace, "Cor Unum", Health Care Workers, and Migrants and Itinerant Peoples. This dicastery, led by Cardinal Peter Turkson of Ghana, launched January 1, 2017, thus, the XXXI International Conference was among the final events hosted by the Pontifical Council for Health Care Workers.

Sabin is grateful to have had the opportunity to work with the Pontifical Council to plan this exciting event. Attention by Pope Francis and other religious leaders could make a tremendous impact on the NTD control and elimination effort at this crucial juncture. As we accelerate toward disease elimination, new partners and creative approaches will be needed to reach the finish line and ensure that the most vulnerable communities are served by our efforts. The involvement of religious leaders and faith-based institutions could be a crucial part of the solution.

Pre-Event Press Conference Bulletin

November 7, 2016

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"Towards a culture of health that is welcoming and supportive at the service of people with rare and neglected pathologies" is the theme of the 31st International Conference of the Pontifical Council for Healthcare Workers (Health Pastoral Care), which will take place in the Vatican's New Synod Hall from 10 to 12 November and was presented this morning in the Holy See Press Office.

The speakers were Msgr. Jean-Marie Mupendawatu and Fr. Augusto Chendi, M.I., respectively secretary and under-secretary of the Pontifical Council for Healthcare Workers (Health Pastoral Care); Dr. Marco Tartaglia, head of the research department on rare diseases and genetic disorders at the Bambino Gesù Paediatric Hospital, Rome; and Dr. Claudio Giustozzi, national secretary of the Italian cultural association "Giuseppe Dossetti: I Valori-Sviluppo e Tutela dei Diritti" ONLUS.

They explained that according to the World Health Organisation (WHO, 2016), a disease is considered rare when it affects one person in two thousand, or fewer. From around five to eight thousand pathologies are defined in this way, of which 80 per cent are of genetic origin, and often life-threatening. It is estimated that around 400 million people worldwide are affected.

The WHO also estimates that more than a billion people, of whom almost half are children, are affected by "neglected" illnesses. The majority have an infectious cause and are widespread in geographical areas with a tropical climate, where the populations live without access to drinking water, with poor hygiene, inadequate housing conditions and limited or no access to healthcare services; in summary, in conditions of poverty that cause grave health problems for the world's poor. This situation poses a great challenge not only from an epidemiological, scientific and clinical point of view, but also from a cultural and political perspective, clearly



indicating the need for responsibility and commitment at global level by all interested parties.

The Church, which throughout her two millennia-long attention for the world of the sick has always been aware of service to the suffering and the ill as an integral part of her mission, intends by organising this conference to place herself at the service of those affected by rare and neglected pathologies, offering a response of an educational, cultural and pastoral nature. The treatment and care of the sick in general and those affected by rare and neglected pathologies in particular are an inescapable work of evangelical corporal mercy. This pastoral urgency, with special attention to healthcare workers and decision-makers, finds in Pope Francis' ecclesial vision a renewed zeal, as demonstrated by the various initiatives and actions promoted and realised in this current Extraordinary Jubilee of Mercy.

The Conference, to be attended by 320 people from more than fifty countries, is structured according to three key themes, which constitute the pedagogical key to its work: reform, to focus on current knowledge both in a scientific and a clinical sense; to treat better and with a welcoming and fraternal approach to the life of the patient; and to protect the environment in which humankind lives. Msgr. Mupendawatu concluded by repeating the Holy Father's words, which appear in the Presentation of the Conference Programme: "The Pope considers it to be a priority for the Church, in this historic moment, to be dynamically 'outbound' to offer concrete witness to Divine Mercy, making herself a 'field hospital' for the 'rejected' who live in every existential, socio-economic, healthcare, environmental and geographic periphery in the world."

The initiatives that form part of the Conference programme will include a meeting of European Catholic Healthcare Institutions, and a photographic exhibition on rare and neglected illnesses that can be visited in the entrance of the Paul VI Hall, from Thursday 10 November.

Media Mentions

Catholic Culture:

[*Equal Access to Care*](#)

Catholic News Agency:

[*What the poor suffer from most happens in developed countries*](#)

Vatican Radio:

[*Vatican event supports people with rare and neglected diseases*](#)

Vatican Radio:

[*Pope Francis: Message to Health Care Workers*](#)

Vatican Radio (in Italian):

[*Card. Parolin: non si abbandonino persone con malattie rare*](#)

(Card. Parolin: do not abandon people with rare diseases)

Zenit:

[*Pope Says Equal Access to Health Care a Question of Justice*](#)

Zenit (in French):

[*«On arrête de produire certains médicaments par manque de rentabilité», déplore le card. Parolin*](#)
("We stop producing certain drugs for lack of profitability," laments the card. Parolin)



Day 1 Conference Highlights

November 10, 2016

Opening of the XXXI International Conference

Introduction

Msgr. Jean-Marie Mupendawatu, Secretary of the Pontifical Council for Health Care Workers (Holy See)

Words of Greeting

- His Eminence Cardinal Peter Kodwo Appiah Turkson, Prefect of the Dicastery for Promoting Integral Human Development (Holy See)
- His Eminence Cardinal Francesco Montenegro, Metropolitan Archbishop of Agrigento and President of the Episcopal Commission for Charity and Health (Italy)
- Hon. Beatrice Lorenzin, Minister of Health (Italy)
- Dr. Mariapia Garavaglia, Chairman of the Luigi Maria Monti Foundation (Italy)
- Dr. Anthony Tersigni, President of the Governing Board of the International Committee of Catholic Health-care Institutions (United States)
- Dr. Anthony Mutsunga, Catholic University of the Martyrs of Uganda (Uganda)
- Yves Bongarçon, Psycho-social worker, Lymphatic Filariasis Program, Sainte Croix Hospital (Haiti)

Prolusion – Neglected Tropical Diseases

21st Century Ancient Afflictions of the Poor and Vulnerable

Dr. Peter Hotez, President, Sabin Vaccine Institute

Official Opening of the XXXI International Conference

His Eminence Cardinal Pietro Parolin, Secretary of State of His Holiness (Holy See)

The Role of Associations of Sick People, Families and Socio/Health-Care and Pastoral Workers

His Eminence Msgr. Nunzio Galantino, General Secretary of the Italian Bishops' Conference (Italy)

Message from the World Health Organization (WHO):

Dr. Dirk Engels, Director of WHO NTD Department (via video message)

Roundtable

The State of the Question – What Can We Know and Do?

First Session

Chair: Dr. Ranieri Guerra, Director of the General Directorate for Health-Care Prevention, Ministry of Health (Italy)

Speakers:

- Epidemiology and Health Care Policies: Dr. Odile Tchangmena Befeuka, Medical Director at the Italian Medicine Agency (Italy)
- Prevention, Treatment and Research: Dr. Samuel Kalluvya, HIV/AIDS Coordinator, The Catholic University of Medicine, Bugando Medical Center (Tanzania)
- Ebola: Dr. Marie Kakicha Kapepela, Pediatrician, Infectious Diseases Unit to Faculty of Medicine, University of Kinshasa (DRC)
- Zika: Dr. Maria Inez Linhares, Vice President, World Federation of the Catholic Medical Associations (Brazil)
- Discussant: Rev. Dr. Mathew Abraham, Director General, Catholic Health Association of India

Second Session

Chair: Prof. Paul D'Arbela, Professor of Medicine and Cardiology (Uganda)

Speakers:

- 10 Neglected Tropical Diseases: Prof. Sr. Monica Luparello, Catholic University of Mozambique (Mozambique)
- Buruli Ulcer: Br. Fiorenzo Priuli, O.H., St. Jean de Dieu Hospital (Benin)
- Leprosy: Prof. Jean-Marie Decazes, Professor of Infective and Tropical Diseases (France)
- Discussant: Rev. Dr. Mathew Abraham, Director General, Catholic Health Association of India

Presentation Highlights

In his introductory address to the conference, **Msgr. Jean-Marie Mupendawatu**, Secretary of the Pontifical Council for Healthcare Workers, shared that the Church invites each and every one of us to be at the service of the poor at the national and international level. On this point, “there is a lot of talk, but little is done – we hold conferences, we hold meetings, but the commitments we make are easily forgotten.” Msgr. Mupendawatu repeated the motto of the conference: to be at the service of people. We must strive to see patients not as numbers, but people, “in the flesh,” and remember that “healthcare for the sick is a form of mercy, an evangelical response to a pastoral need.”

Beatrice Lorenzin, Italian Minister of Health, opened her address with the assertion that “The right to health means the right to live in a dignified way,” explaining that healthcare efforts must be focused not only on saving lives and preventing symptoms but also on protecting the dignity of patients. She shared information about Italy’s efforts to expand care for individuals and families affected by rare diseases and praised global progress against NTDs, calling this effort a great example of international collaboration in public health and calling for the commitment of all institutions involved in healthcare – national, multinational, religious and secular – to achieve these goals.

Following the proslution on NTDs by Dr. Peter Hotez (reproduced in full on pages 9-12), **Cardinal Pietro Parolin**, Secretary of State of the Holy See, officially opened the conference on behalf of the Holy See. In his remarks, he referenced that with more than 1 billion people estimated to be infected with NTDs, “Just this figure should prompt us to do more so these people are not abandoned to a fate of marginalization and suffering.” He emphasized that the response to NTDs goes beyond science: “There is a link between NTDs and the condition of extreme poverty. Not just treatment, but justice” – a need for access to clean water, the elimination of stigma, and better living conditions to prevent disease.

He summarized this reality concisely: “Tropical diseases rise out of poverty and generate further poverty, thus preventing the social promotion of the sick.” Cardinal Parolin concluded by emphasizing the need for international assistance to governments of countries affected by NTDs, because “governments are responsible for the health of their citizens,” called for efforts to raise awareness of NTDs in the media and on social media to increase global solidarity with those affected, and emphasized the commitment of the Catholic Church to provide help to all people suffering from disease – an essential element of the Christian vocation.

“Against all odds,

we are making remarkable progress [against NTDs], and we want to sustain this – but we cannot do it alone. At WHO, we are glad to note the increased interest of the Pontifical Council in diseases that continue to affect the poor. The Vatican’s engagement in the fight against extreme poverty has been exemplary. We sincerely believe that faith-based organizations and colleagues gathered in this assembly can help to fulfill the promise of the sustainable development goals in the fight against these poverty-related diseases.”

– Dirk Engels, Director of WHO NTD Department
(via video message)



Neglected Tropical Diseases: 21st Century Ancient Afflictions of the Poor and Vulnerable

Remarks by Dr. Peter Hotez

President, Sabin Vaccine Institute

Dean, National School of Tropical Medicine, Baylor College of Medicine

November 10, 2016

I'm deeply appreciative of the honor to present here at the Vatican and to the Pontifical Council for Health Care Workers. I'm especially grateful to Msgr. Jean-Marie Mupendawatu, the Secretary of the Pontifical Council for Health Care workers for the invitation.

Today I am going to introduce a group of diseases I sometimes call "the most important diseases you have never heard of," what we first named back in the early 2000s as the 'neglected tropical diseases' or NTDs. These are diseases borne of poverty and conflict – two challenges at the heart of the social mission of the Catholic Church.

The concept of the NTDs was born out of the Millennium Development Goals (MDGs) first launched in 2000, when infectious diseases were highlighted as through Goal 6, "to combat AIDS, malaria, and other diseases". Whereas AIDS and malaria benefited from massive overseas development assistance, those called "other diseases" were ignored or neglected. In response, we created the framework of NTDs to embrace a group of 13-14 chronic and debilitating parasitic and related infections. NTDs are the most common diseases of the poor; one in six people in the world have at least one NTD.

Through the Global Burden of Disease Study we have now derived specific numbers for the prevalence of the world's NTDs, led by intestinal helminth infections, schistosomiasis, lymphatic filariasis, dengue, and foodborne trematode infections.

Why do we care so much about the NTDs? NTDs promote poverty. NTDs can cause blindness, horrible swelling of the limbs and even death. Schistosomiasis is the second largest parasitic killer after malaria, trachoma is the leading cause of preventable blindness. Lymphatic filariasis causes extreme, debilitating swelling of the legs and genitals. Intestinal worms such as ascariasis, hookworm and trichuriasis impede children's cognitive and physical development, and can make them too sick to attend school. Schistosomiasis and other NTDs disproportionately affect girls and women making them more susceptible to HIV/AIDS and other catastrophic infections. The stigma associated with some of the most disfiguring neglected tropical diseases isolates patients from their families and communities. These adverse health consequences translate to lost economic productivity and development opportunities, trapping families and communities in a cycle of disease and poverty.



NTDs are ancient afflictions described in the Bible and other ancient texts. Today, NTDs are having a horrific impact on the world's Christian populations living in poverty. Christian majority countries account for most of some of the highest disease burden NTDs such as Chagas disease, sleeping sickness, schistosomiasis, and others. Many of the most common NTDs can be treated and prevented with existing drugs at an extremely low cost. A few, such as lymphatic filariasis and onchocerciasis, could be eliminated entirely if everyone at risk received treatment. Pharmaceutical companies have donated billions of doses of medication and have pledged to donate billions more, but increased investment is needed to expand treatment programs and ensure the delivery of these drugs to everyone at risk.

This global effort guided by the World Health Organization has scaled up NTD treatment programs in the last decade. This is now the largest public health program in the world. More than 978 million people were treated last year for NTDs. But that is still just half of people living in at risk communities who require medication. Treatment programs are underfunded, leaving hundreds of millions of people without access to these essential medicines, despite the low cost of treatment – just \$0.50 per person, per year.

This global effort to control and eliminate NTDs has successfully reduced the prevalence of some NTDs such as lymphatic filariasis, onchocerciasis and trachoma. Just this year, four countries in the Western Pacific Region eliminated lymphatic filariasis. In the Americas, onchocerciasis has been eliminated from all but one region on the border of Venezuela and Brazil. These are great successes – millions free from disability and unnecessary suffering. But for other neglected tropical diseases, progress has stalled. Parasites such as hookworm and trichuriasis have barely decreased and the prevalence of schistosomiasis has actually increased. For some NTDs, such as hookworm, trichuriasis and schistosomiasis, existing drugs are less effective and will not be sufficient to achieve elimination. New strategies and tools are needed. Vaccines such as those currently in development by the Sabin Vaccine Institute could be powerful tools. Yet this research and development is severely underfunded.

Today, we are entering a new era of global health and development. The Sustainable Development Goals look at health in the context of many other factors including climate change and Earth sciences and the social fabric. Likewise, the Catholic Church is advancing this concept through the establishment of the new Dicastery for Promoting Integral Human Development.

We are adjusting our development strategy because the face of poverty is changing. NTDs are found among the poor, even those living in wealthy economies, especially G20 nations. This map shows the concentrated pockets of poverty-related neglected diseases in the world's wealthiest countries. Our old norms of global health focused in developing versus developed nations are no longer accurate. In a new book just published I refer to this changing paradigm as 'blue marble health.' As Pope Francis put it, "On the one hand we are seeing a reduction in absolute poverty, on the other hand we cannot fail to recognize that there is a serious rise in relative poverty, that is, instances of inequality between people and groups who live together in particular regions."

Today the wealthiest economies of Latin America are found in the G20 nations of Argentina, Brazil and Mexico, yet these three nations account for most of the world's Chagas disease cases led by Argentina. Less than 1% of people living with Chagas disease in these wealthy nations have access to essential NTD diagnostic and medicine. Or if we look to Brazil, while it is Latin America's largest economy, the northeastern region that includes Pernambuco, Bahia, Paraiba, Ceara States also accounts for the single largest concentration of NTDs in the Americas led by schistosomiasis, leishmaniasis, Chagas disease and dengue, among others. Therefore it's no surprise that Zika virus infection, with devastating effects for mothers and their unborn children, concentrated in this same region, where poverty especially urban poverty is severe and widespread.

We need prophetic voices in these countries to call attention to the health problems affecting their poorest citizens. Catholic leaders could be a witness to this hidden suffering, urging policymakers to take strong action and invest in treatment and prevention.

It is clear that poverty is one key driver of NTDs; the other is conflict. For example, Ebola virus emerged due to the political destabilization following conflict, and now these same forces are in play in the conflict zones of the Middle East and North Africa, including Syria, Iraq, Yemen, and

Libya. This region appears to be likely to become the next big 'hot zone' of emerging NTDs. We are witnessing a catastrophic situation with leishmaniasis for example where there have been hundreds of thousands of disfiguring cases that the locals call "Aleppo evil". In this new era of development, as we seek an integrated approach to combat the diseases that thrive in poverty and conflict, we urgently need new diagnostics, drugs, and vaccines to end the suffering caused by these diseases.

The Sabin Vaccine Institute is an organization of scientists, researchers and advocates dedicated to reducing needless human suffering from vaccine-preventable diseases and NTDs. Since its founding in 1993 in honor of Dr. Albert B. Sabin, the developer of the oral polio vaccine, Sabin has been at the forefront of global efforts to eliminate, prevent and cure infectious and neglected tropical diseases.

At Sabin, we are leading efforts to develop half a dozen vaccines to combat NTDs affecting the world's poorest people. We relocated our vaccine development team to Texas, where diseases once thought to be limited to low-income countries are now found in areas of extreme poverty in our own backyard. I established the National School of Tropical Medicine at Baylor College of Medicine to advance efforts against these diseases. We are developing a vaccines for Chagas that will hopefully soon enter the clinic. We're also developing vaccines for

"Greater investment today will lay the foundation for tomorrow's new and better vaccines to tackle neglected tropical diseases."

Dr. Peter Hotez, Sabin Vaccine Institute

"A coordinated push at every level of the Church could be the tipping point in the effort to control and eliminate these diseases for good."

Dr. Peter Hotez, Sabin Vaccine Institute

leishmaniasis, schistosomiasis and human hookworm. Increased funding is needed in order to help increase momentum for the development and testing of new vaccines, advance products currently in development and create a sustainable path to deliver them to people in need worldwide. Greater investment today will lay the foundation for tomorrow's new and better vaccines to tackle neglected tropical diseases.

We call our NTD vaccines "antipoverty" vaccines because of their potential not only to improve health but also lift the poorest people out of poverty. The global effort to control and eliminate NTDs shares three key principles with the Church's social teaching: the life and dignity of the human person, the preferential option for the poor and vulnerable, and the commitment to the common good.

It is clear that NTDs are an affront to human dignity and obstacle to human flourishing. No one should suffer unnecessarily from these ancient diseases in the twenty-first century. NTDs make a preferential option for the poor and vulnerable, targeting marginalized communities denied basic human rights such as health care, clean water and education. To succeed in the effort to end extreme poverty, the global community must make a preferential option for the poor and vulnerable by scaling up the effort to fight NTDs. One of the most basic things we can do to overcome what Pope Francis has termed the "globalization of indifference" and advance the common good is to take decisive action against NTDs: expanding treatment coverage to reduce prevalence today, advancing research and development of new tools to achieve elimination in the coming years, and in the interim, ensuring the basic rights and dignity of patients, combatting all forms of stigma and discrimination.

The unnecessary suffering of over one billion people is a challenge to the conscience of the Church and the world. As one of the largest social service providers in the world and as an institution with a powerful moral voice, the Catholic Church is in a unique position to advance the fight against NTDs in three ways.



First, Catholic institutions can directly support NTD treatment and prevention programs, working through the Church's vast network of hospitals, health centers, schools, and parishes to reach every at-risk community with treatment and encourage healthy behaviors to prevent NTDs. Second, Church leaders in communities affected by NTDs can minister to sick individuals and their families and tackle stigma and discrimination. Third, the Church can mobilize much-needed financing by encouraging charitable giving by Catholic institutions and individuals and public investment by world leaders to support NTD treatment and advance research. Indeed, a coordinated push at every level of the Church could be the tipping point in the effort to control and eliminate these diseases for good.

For this reason, it has been an honor to speak at this conference. I am deeply grateful for this opportunity to share with you a vision for how we can one day eliminate the world's NTDs as a powerful expression of solidarity with the poor.

Day 2 Conference Highlights

November 11, 2016

Roundtable

Socio-Political, Economic and Juridical-Ethical Aspects from the point of view of Respect for the Lives, the Dignity and the Rights of Patients and the Commitment to be Welcoming and Supportive

Chair: Prof. Margaret Scotford Archer, President of the Pontifical Academy of Social Sciences (United Kingdom)

Speakers:

- The Human, Social, Political and Economic Problems of People with Rare Pathologies: Dr. Krzysztof Łanda, Undersecretary of State, Ministry of Health (Poland)
- Legislation and Ethics to Protect the Lives, the Dignity and the Rights of Patients, and the Responsibilities of Institutions: H.E. Msgr. Vincenzo Paglia, President of the Pontifical Academy for Life (Holy See)
- The Mission of EURORDIS at the Service of People Living with Rare Diseases: Ms. Simona Bellagambi, Member of EURORDIS Board (Italy)
- The Role of the Church and Faith Communities in the Recent Ebola Epidemic in Africa: Fra' Pascal Ahodegnon, Medical Doctor (Benin)
- USAID's Commitment to the Fight against Neglected Tropical Diseases: Dr. Ariel Pablos-Méndez, Assistant Administrator for Global Health, Child and Maternal Survival Coordinator (USA)
- Discussant: Prof. Jacques Simporè, Professor of Genetics and Molecular Biology at the University of Ouagadougou and Rector of the University of Thomas Aquinas, Director of the Centre for Biomolecular Research - CERBA/LABIOGENE, Consultor of the Pontifical Council for Health Care Workers (Burkina Faso)

Roundtable

The Question of Medical Products and Access to Treatment

Chair: Prof. Maria Paola Costi, Department of Life Sciences, the University of Modena and Reggio Emilia (Italy)

Speakers:

- Access to Medicines for the treatment of neglected tropical diseases: Dr. Sylvie Fonteilles Drabek, Executive Vice President, Head of Legal of Medicines for Malaria Venture (Switzerland)
- Progress towards the IRDiRC Goals: 200 New Treatments for Rare Diseases by 2020: Dr. Paul Lasko, International Rare Disease Research Consortium - IRDiRC, Scientific Director of the Institute of Genetics, Canadian Institutes of Health Research (Canada)

Roundtable

Care that respects patients and the environment: A brief re-reading of the Encyclical Laudato si'

Introducing the Dialogue and the Discussion: Dr. Antonio Maria Pasciuto

Discussant: Dr. Antonio Maria Pasciuto, Specialist Medical Doctor in Environmental Medicine (Italy)

Roundtable

Good Practices

Chair: Fr. Leocir Pessini, Superior General of the Camillians (Brazil)

Speakers:

- Buruli Ulcer: Dr. Roch Christian Johnson, Medical Adviser, Fondation Raoul Follereau (France)
- Leprosy: Dr. Tatsuya Tanami, Executive Director the Nippon Foundation (Japan)
- SAFE Strategy to Defeat Trachoma in North Ethiopia: Dr. Babar Qureshi, Director of the CBM Neglected Tropical Diseases Program, CBM Italy
- Tuberculosis: Dr. Mario C. Raviglione, Director of the Global Tuberculosis Programme, World Health Organization (Switzerland)
- Research, Solidarity and Medicines: Dr. Lelio Marmora, Executive Director, UNITAID (Switzerland)

- Associations: Dr. Nicola Spinelli Casacchia, President of the Italian Federation
- Discussant: Dr. Mario Angi, President of Christian Blind Mission - C.B.M., Consultor of the Pontifical Council for Health Care Workers (Italy)

Presentation Highlights

Opening the morning roundtable, **Msgr. Vincenzo Paglia**, President of the Pontifical Academy for Life, stated, “This conference addresses the periphery of medicine, bringing it into the limelight...The periphery of medicine should become the center. The rights of the poor are sacrosanct and of priority importance.” Later in the roundtable, **Dr. Ariel Pablos-Méndez**, Assistant Administrator for Global Health, United States Agency for International Development (USAID), described how the U.S. government is putting this principle into practice through the USAID NTD Program. The program has delivered more than 1.6 billion treatments to 743 million people and plans to deliver another 1.3 billion treatments by 2020. The program’s scope has recently expanded beyond mass drug administration to include morbidity management and disability prevention in an effort to better serve all individuals affected by NTDs.

Following the morning roundtable, a video about the conference featuring Sabin footage and comments from **Msgr. Mupendawatu** was screened.

During the afternoon, representatives of several leading foundations, non-governmental development organizations, and international financing organizations discussed their approach to NTD prevention and treatment. **Dr. Roch Christian Johnson**, Medical Advisor for the Raoul Follereau Foundation, described the foundation’s support of research into a ground-breaking new antibiotic treatment which has revolutionized treatment for for buruli ulcer. Previously, surgical excision and skin grafting were the only medical treatments available for the disfiguring disease.

Dr. Tatsuya Tanami, Executive Director of the Nippon Foundation, described the historic effort over the past few decades to end the suffering caused by the NTD Hansen’s Disease. The Nippon Foundation has contributed more than \$200 million to disease control since 1974, curing millions of people of the disfiguring disease commonly known as leprosy.

Dr. Babar Qureshi described how trachoma prevention and treatment is being mainstreamed into the primary healthcare and education system in Ethiopia to accelerate the country’s effort to eliminate the NTD. Globally, 125 million fewer people are at risk of trachoma than just five years ago, and Ethiopia’s program is a model for other countries looking to continue this trend.

Dr. Mario Raviglione, Director of the World Health Organization Global Tuberculosis Program, and **Dr. Lelio Marmora**, Executive Director of UNITAID, concluded the panel by describing progress against tuberculosis and HIV/AIDS since the start of the new millennium and the need for new resources and accelerated research to control these interrelated global epidemics.

“When we have the influence and the power and the money to change things,

we must act to change the reality.”

— Dr. Lelio Marmora, Executive Director, UNITAID



Day 3 Conference Highlights

November 12, 2016

Roundtable

Roundtable: An Outlook of Hope on the Future: Reasons, Conclusions and Recommendations

Speakers:

- The Reasons for Hoping in a Better Future: Prof. Giuseppe Novelli, Rector of the Tor Vergata University of Rome, Director of U.O.C. of Medical Genetics Laboratory of the University Hospital of Tor Vergata (Italy)
- Conclusions and Recommendations: Prof. Fr. Michele Aramini, Lecturer in Theology at the Catholic University of the Sacred Heart - Milan (Italy)
- General Observations: His Eminence Cardinal Peter Kodwo Appiah Turkson

Presentation Highlights

Fr. Michele Aramini, Lecturer in Theology at the Catholic University of the Sacred Heart, presented seven conclusions and recommendations gleaned from the conference proceedings, including recommendations that governments should increase financing for research on rare and neglected diseases, that wealthy nations should assist developing nations with efforts to combat these diseases, and that the media should increase coverage of the impact of rare and neglected diseases to influence public opinion and policy. He concluded, "Health is a primary element of the concept of justice." Cardinal Peter Turkson, Prefect of the Dicastery for Promoting Integral Human Development, closed the remarks by reiterating Pope Francis' personal interest in the conference topic and thanking all speakers and participants for their important work.

Message from Pope Francis

Read by conference participant
(reproduced in full pages 16-18)

Closing Reflections

To close the conference, Msgr. Mupendawatu invited conference participants to share closing reflections. **Dr. Peter Hotez** shared a timely reflection on the impact of recent political changes in the United States and United Kingdom - two key supporters of the fight against NTDs: "The reason this conference is so important is because the Vatican, the Church, has an opportunity to fill this void, to fill this vacuum," he said. "By hosting this conference today, you've told the world that neglected diseases and rare diseases are important. The leadership of the Church is going to be needed more than ever. And the task ahead is not easy. We heard over the last three days that these are complex issues. They have complex social determinants. We're going to need the Pontifical Academy of Social Sciences to help us. These are complicated human rights issues. We're going to need the Pontifical Academy for Life to help us. There's a huge research and development agenda that the world is ignoring - we're going to need the Pontifical Academy of Sciences. There's a massive geopolitical agenda in order to get the other G20 countries on board - having the Secretary of State here on the first day, I think, historically could prove to be very important. So, while there are potentially dark days ahead, the good news is I want to congratulate you on your leadership to take this on. When others are pivoting away, you're marching into the fire." His reflection received a standing ovation from conference participants.

"The reason conference is so important is because the Vatican, the Church, has an opportunity to fill this void, to fill this vacuum. By hosting this conference today, you've told the world that neglected diseases and rare diseases are important.

The leadership of the Church is going to be needed more than ever."

— Dr. Peter Hotez, Sabin Vaccine Institute

Message of His Holiness Pope Francis to Participants in the 31st Conference of the Pontifical Council for Health Care Workers

To the Most Reverend Monsignor
Jean-Marie Mupendawatu
Secretary of the Pontifical Council for Health Care Workers

November 12, 2016

I wish to send my cordial greetings to those taking part in the thirty-first international conference on the subject 'Towards a Culture of Health that is Welcoming and Supportive, at the Service of People with Rare and Neglected Pathologies', organised by the Pontifical Council for Health Care Workers, which I thank for this initiative. I also address grateful thoughts to the memory of my much lamented brother in the episcopate, H.E. Msgr. Zygmunt Zimowski, the former President of the Pontifical Council, who returned to the House of the Father last July.

Qualified experts, from every part of the world, have come together to explore the subject of 'rare' pathologies and 'neglected' diseases in their various aspects: from the medical-epidemiological to the socio-political and from the economic to the juridical-ethical. The conference intends to engage in a survey of the present situation, as well as an identification and a re-launching of practicable guidelines for action in this special medical/health-care scenario; having as founding values respect for the lives, the dignity and the rights of patients, together with a welcoming and supportive approach; and producing strategies for care and treatment that are moved by a sincere love for the actual person who suffers – from a 'rare' or 'neglected' disease as well.

The data that are available on these two chapters of medicine are emblematic. The most recent calculations of the World Health Organisation indicate that 400 million people in the world as a whole suffer from diseases defined as 'rare'. The scenario of 'neglected' diseases is even more dramatic because they affect over a billion people. They are for the most part infectious diseases and they are widespread amongst the poorest populations of the world, often in countries where access to health-care services is insufficient to cover essential needs, above all in Africa and Latin America, in areas that have a tropical climate, with insecure drinking water and deficient hygienic/alimentary, housing and social conditions.

The challenge, from an epidemiological, scientific, clinical/care, hygienic and economic point of view is, therefore, enormous because it involves responsibilities and commitments on a global scale: international and national health-care and political authorities, health-care workers, the biomedical industry, associations of citizens/patients, and lay and religious volunteers.

This is an enormous challenge, but not an impossible one. Given the complexity of the subject, indeed, a multidisciplinary and joint approach is necessary; an effort



that calls on all the human realities involved, whether institutional or otherwise. Amongst them there is also the Catholic Church which has always found a motivation and impulse in her Lord, Jesus Christ, who was crucified and rose again, the figure both of the patient ('Christus patiens') and the physician ('Christus medicus', the Good Samaritan).

At this point, I would like to offer some observations that can contribute to your reflections.

The first is that if the human person is the eminent value, it follows that each person, above all a person who suffers, because of a 'rare' or 'neglected' disease as well, without any hesitation deserves every kind of commitment in order to be welcomed, treated and, if possible, healed.

The effective addressing of entire chapters of illness, as is the case with 'rare' and 'neglected' diseases, requires not only qualified and diversified skills and abilities in health-care but also ones that are beyond health care – one may think of health-care managers, of administrative and political health-care authorities, and of health-care economists. An integrated approach, and careful assessments of contexts directed towards the planning and implementation of operational strategies, as well as

the obtaining and management of the necessary sizeable resources, are required. At the base of every initiative, however, lies, first and foremost, free and courageous good will directed towards the solving of this major problem of global health: an authentic 'wisdom of the heart'. Together with scientific and technical study, the determination and wisdom of those who set themselves to work not only in the existential fringes of the world but also in its fringes at the level of care, as is of often the case with 'rare' and 'neglected' diseases, are, therefore, crucial.

Amongst the many who give of themselves generously, the Church, as well, has always been active in this field and will continue with this exacting and demanding pathway of nearness to, and the accompanying of, the person who suffers. It is no accident, therefore, that this thirty-first international conference wanted to adopt the following key words to communicate the sense – understood as meaning and direction – of the presence of the Church in this authentic work of mercy: to inform, in order to establish the state of present knowledge at a scientific and clinical/care level; to care for the life of patients in a better way in a welcoming and supportive approach; to steward the environment in which man lives.

“One can identify realistic, courageous, generous and supportive solutions to addressing even more effectively, and to solving, the health-care emergency of ‘rare’ and ‘neglected’ diseases.”

Pope Francis

The relationship between these diseases and the environment is decisive. Indeed, many diseases have genetic causes; in the case of others, environmental factors have a major importance. But even when the causes are genetic, a polluted environment acts as a multiplier of damage. And the greatest burden falls on the poorest populations. It is for this reason that I want once again to emphasise the absolute importance of respect for, and the stewardship of, the creation, our common home.

A second observation that I would like to bring to your attention is that it remains a priority of the Church to keep herself dynamically in a state of ‘moving outwards’, to bear witness at a concrete level to divine mercy, making herself a ‘field hospital’ for marginalised people who live in every existential, socio-economic, health-care, environmental and geographical fringe of the world.

The third and last observation relates to the subject of justice. Although it is true that care for a person with a ‘rare’ or ‘neglected’ disease is in large measure connected with the interpersonal relationship of the doctor and the patient, it is equally true that the approach, at a social level, to this health-care phenomenon requires a clear application of justice, in the sense of ‘giving to each his or her due’, that is to say equal access to effective care for equal health needs, independently of factors connected with socio-economic, geographical or cultural contexts. The reason for this rests on three fundamental principles of the social doctrine of the Church. The first is the principle of sociality, according to which the good of the person reverberates through the entire community. Therefore, care for health is not only a responsibility entrusted to the stewardship of the person himself or herself. It is also a social good, in the sense that the more individual health grows, the more ‘collective health’ will benefit from this, not least at the level, as well, of the resources that are freed up for other chapters of illness that require demanding research and treatment. The second principle is that of subsidiarity which, on the one hand, supports, promotes and develops socially the capacity of each person in attaining fulfilment and his or

her legitimate and good aspirations, and, on the other, comes to the aid of a person where he or she is not able on his or her own to overcome possible obstacles, as is the case, for example, with an illness. And the third principle, with which a health-care strategy should be marked, and which must take the person as a value and the common good into account, is that of solidarity. On these three cornerstones, which I believe can be shared by anybody who holds dear the eminent value of the human being, one can identify realistic, courageous, generous and supportive solutions to addressing even more effectively, and to solving, the health-care emergency of ‘rare’ and ‘neglected’ diseases.

In the name of this love for man, for every man, above all for suffering man, I express to all of you, participants in the thirty-first international conference of the Pontifical Council for Health Care Workers, the wish that you will have a renewed impetus and generous dedication towards sick people, as well as a tireless drive towards the greatest common good in the health-care field.

Let us ask the Most Holy Mary, Health of the sick, to make the deliberations of this conference of yours bear fruit. To her we entrust the commitment to making increasingly human that service which, every day, the various professional figures of the world of health perform for suffering people. I bless from my heart all of you, your families, and your communities, as I do those whom you meet in hospitals and nursing homes. I pray for you; and you, please, pray for me.

From the Vatican, 12 November 2016



The Way Forward

Reaching the NTD control, elimination and eradication goals laid out in the World Health Organization NTD Roadmap will require partnership on a historic scale. The London Declaration on NTDs formalized and expanded a unique public-private partnership model that has driven NTD treatment coverage rates to historic highs – but much more remains to be done to meet the targets in full. Local religious leaders could play a unique role in mobilizing participation in treatment campaigns, and public support by faith leaders at the national and international level could build advocacy support for increased funding and policy attention.

In short, the discussions begun at the Pontifical Council for Healthcare Workers' XXXI International Conference could bear fruit in the form of new partnerships to drive progress against NTDs – in the words of Pope Francis, “free and courageous good will directed towards the solving of this major problem of global health.”



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